Thinking About Dementia

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Published by Rutgers University Press


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The narrative turn in the study of aging has brought forth a variety of nonpositivist, nonrealist approaches to examining an elder’s life story within the terms of the story itself, independent of its truth content. Beginning with the early 1980s, anthropology witnessed a flood of studies concerning the life history approach (cf. Bertaux 1981; Crapanzano 1980; Shostak 1981). By 1988, however, the influence of illness in the construction of one’s life history received little attention (Kaufman 1988, 217). Since then, bolstered by interpretive approaches to narrative in anthropology (e.g., Rabinow and Sullivan 1987), as well as theory and methods from literary criticism (Bakhtin 1981), philosophy (Ricoeur 1981, 1984), and cognate disciplines (Polkinghorne 1988, 1996; Cohler 1993; Bruner 1991; White 1980, 1987), social scientists have increasingly examined the place of narrative production in the construction of meaning for persons confronting illness (Kaufman 1988; Mattingly 1998), disruption (Becker 1997; Lovell 1997), or the frailties of aging (Gubrium 1993; Kaufman 1986; Rubinstein 1988, 1990; Rubinstein, Kilbride, and Nagy 1992; Holstein and Cole 1996).

Whereas many clinical applications of reminiscence and developmental understandings of the life course have been informed by positivist notions that view language as direct reflections of a fixed coherent self, recent autobiographical works in gerontology (Gubrium 2000, 2001; Gubrium et al. 1994; Birren et al. 1996; Coleman 1999; Kenyon 2001) or at large (Climo and Cattell 2002) have been shaped by more critical approaches. Studies problematizing the notion of a coherent fixed self (Ewing 1990; Gubrium and Holstein 1995) have been informed by a postmodern appreciation of the dialogic production (Bakhtin 1981) of multiple ever changing selves produced in diverse contexts.
The self-consciousness demanded by self-critics of ethnography (Clifford and Marcus 1986; Marcus and Fischer 1986) has stimulated the emergence of native voices (first-person accounts of indigenous, subaltern, or other), while soundly delivering the postmodern message that the researcher is not revealing “truth,” only her own particular reading of the field as text. The influence of analyses of text-based (not natural-language-based) discourses from disciplines such as literary studies has further directed studies of narrative away from realist concerns with how well they reflect “actual experience” or the narrator’s inner life, or with how accurately the narrator’s recollections portray actual events, objectively validated by external evidence. Increasingly, narratives are being examined as texts that cohere within themselves, independent of any external validity of their truth value.

Most analyses of life stories in gerontology, however, have concerned elders who are not cognitively impaired, perhaps because this group has been seen as more capable of reflecting upon the past in constructing their own stories. For these elders, life narratives have been appreciated for providing coherence, resolution, or direction to the condition of their current lives independent of the authenticity of the content of their narratives. When elders are cognitively impaired, however, questions arise about their capacity to produce a coherent and authentic life story, even though authenticity is not ordinarily a concern. Perhaps the powerful influence of the biomedical model, with its realist emphasis on objective evidence, has inhibited efforts to collect life narratives from cognitively impaired elders, in spite of the contention of nonpositivist narrative studies that the need for external validation is unnecessary or irrelevant (cf. Denzin 1989; Bruner 1991; Polkinghorne 1996). Even more likely, the attention that biomedicine has drawn to decaying brains and loss of reason in the senile elderly has led researchers to discount these elders’ capacities to produce meaningful discourse and has dissuaded them from exploring their life histories.

Thus, with few exceptions (Hamilton 1994; Sabat 1991, 1999; Crisp 1995), there has been limited attention to investigating life stories of persons with dementia. This chapter will contribute to knowledge in this area through the discussion of the life story of one elderly woman with dementia. After describing the study, the narrative, and the context of its production, I will examine the extent and nature of coherence in her story, using formal textual and nontextual criteria. Through these criteria I will consider the relevance of facticity (or “truth”) to coherence in performance, text, and personal integration. I will also examine the meaning of the narrative in light of the existential and material conditions of its production. The chapter will conclude with a brief discussion about the limitations of postmodernist approaches to the study of narratives of elders with dementia and consider both the gains and possible risks of externally validating the stories of these elders.
Research Considerations

The Setting

The study took place over a nine-month period from September 1993 to July 1994. The site was a locked forty-bed special care unit of a five-hundred-bed private nursing home complex in the northeastern part of the United States. Although mainly Jewish, the residents varied in socioeconomic background and country of birth. The affiliation and close proximity of the nursing home to a well-regarded hospital was a major source of attraction for many families. The special care unit was one of two identically designed units that together housed the most severely cognitively and behaviorally impaired elders in the nursing home.

The unit, Morgan II, was intermittently noisy because of the degree of disinhibition and disturbance of its residents. Disturbed behaviors included frequent repetitiveness, verbal aggressiveness, physical combativeness, and undressing in public. Despite the extreme behaviors of its occupants, this unit had an excellent reputation in the community. However, elders rarely entered the unit directly from the community. Rather, they were transferred there from other units in the nursing home, because of deterioration in their condition or escalation of disturbed behaviors.

The residents were overwhelmingly female, at a rate of 85 percent, about 10 percent higher than the national average for nursing homes. They ranged in age from 68 to 98 (with both extremes being males). The median age of all residents was 88.5. Fourteen residents were in their 90s, twenty-one in their 80s, and four in their 70s; a single male was in his 60s.

Methodology of the Larger Study

The purpose of the project was to study qualitatively the communicative interactions of residents with dementia who manifested seriously disturbed behaviors. The goal was to examine the specific contexts in which the disturbed behaviors occurred, evolved, and resolved or escalated in order to determine whether they may have represented failed efforts at communicating rather than, or in addition to, organic deterioration.

I spent approximately nine months on the unit. My methodology was ethnographic and included participant observation; detailed recording of observations; and informal and semistructured interviews with the members of the staff (everyone from housekeepers to physicians), family members, visitors, and wherever possible, the residents themselves. I conducted observations on a daily basis. Although the majority of these observations were conducted during the day shift (7:00 A.M. to 3:00 P.M.) and during several hours of the evening shift (3:00 P.M. to 11:00 P.M.), there were also many days when I stayed throughout the second shift and part of the night shift (11:00 P.M. to 7:00 A.M.). There were also
occasions when I spent twenty-four consecutive hours on the unit in order to observe residents whose disturbances had no predictable pattern, or who would be disruptive after 11:00 P.M. The twenty-four-hour stays gave me a fuller flavor of the flow of life on the unit, offering me a closer look at the way the residents experienced it every day of their lives.

Before selecting the unit for study, I first spent time visiting it and speaking with the head nurse and support staff to ensure that the residents would be appropriate for my purposes. On the day that I formally began my research, the assistant director of nursing introduced me to the unit staff, affirming the administration’s interest in cooperating with the study. Shortly after arriving on the unit, I described my research focus to the staff and to residents’ families (persons designated as responsible parties and others whom I might eventually interview). I explained to them how I would be probing into areas that they might think were irrelevant but that this was necessary for gaining a fuller picture of the context in which disturbances occurred. I also explained that I might appear “nosy” at times, but reminded everyone that the areas into which I inquired were necessary for my study. As the study progressed, the staff and family members were generally cooperative, but a few of the nursing assistants were not very forthcoming, because, despite my efforts to convince them otherwise, they continued to suspect that I was a spy for the administration.

Whenever possible, I wrote my field notes immediately following a conversation or observation to ensure the fullest retention of details. If much activity had caught my attention but I was unable to document my observation at that time, I wrote a brief outline that identified the points that I needed to develop. After leaving the unit, I elaborated on the outline.

I kept my field notes in two separate files. A general file documented my detailed observations about life on the unit. This included observations about interactions between the many persons who lived, worked, or appeared there; caregiving routines; work organization; and of course, disruptive behaviors. I also kept a file for each of six residents I chose for more intensive, focused study. These residents typically manifested the most disruptive behaviors, some by fighting with the staff or other residents, others by making great demands on staff time. In addition to the ethnographic research, I studied the current and past medical records of Morgan II residents in order to gain some understanding of how their condition, including their disturbed behaviors, had changed over time.

Before selecting six residents for intensive study, I spent one month making general observations and inquiries of the unit staff. I spoke with the head nurse of the unit, a registered nurse, and the care managers, generally licensed practical nurses, from every shift. In addition, I spoke with nursing assistants, who have the most direct contact with residents, to obtain their assessments about the most disruptive, behaviorally disturbed residents. A resident might be quiet
on two shifts but terribly disruptive at 3:00 A.M., so I made a point to talk with staff, especially nursing assistants from every shift. I jotted down lists of their candidates, asking for reasons for their selection. I then compared names on the lists to see who most frequently appeared, with the plan to choose those who were identified most often as being “disruptive.”

Focusing on Mrs. Fine

Selecting Mrs. Fine for Intensive Study

Among the main contenders for intensive study was Mrs. Fine, an eighty-five-year-old woman who had been admitted to the home almost three years earlier. Mrs. Fine was identified as being agitated and aggressive with other residents to whom she felt superior. During mealtimes she would compare her food with that of other residents and complain. She would frequently hit other residents or throw food or beverages at them. Targets were residents whose behaviors were visibly disturbed or to whom for some reason she took a dislike. Her behavior had been getting more aggressive in recent weeks, so she appeared on most of the “most disturbed residents” lists I had collected. Mrs. Fine was also known for getting very upset in her single room, where she commonly stayed alone. She would often scream that someone had been going through her belongings and that something valuable was missing. She was also known to suffer from delusions and to hallucinate at times, insisting that a man had entered her room. She would occasionally be up at night, yelling intermittently between naps. Most recently, she had begun to disrobe and occasionally to display exhibitionist behavior.

In addition, Mrs. Fine had a severe expressive aphasia, a language disturbance resulting from focal lesions (Thompson 1987, 146), with word-finding difficulties that left her tearful and frustrated when they interfered with her efforts to speak. The range and extent of her disturbances and the general agreement from the staff about them had convinced me to include her in my study.

Mrs. Fine’s Medical History

Mrs. Fine presented with a somewhat unusual medical history, inconsistent diagnoses, and a history of frequent moves within the facility. About a year prior to her admission to the nursing home, she had become confused, suffered a stroke, and fell and broke her hip. Subsequently she experienced periods of depression and delirium, both involving confusion and hallucinations. These led to two brief psychiatric hospitalizations in the year before her admission to the nursing home.

Mrs. Fine was admitted to the nursing home with a diagnosis of major depression, multi-infarct dementia associated with her stroke, and periodic delirium (paranoia, delusions, and hallucinations). She also had arthritis and a
history of falls. While continent at the time, she performed very poorly on a
cognitive exam, unable to identify her location, age, or married name. She also
indicated that her husband had died one year ago, when he had actually died
twenty years ago.

During her stay at the home, her dementia received various diagnoses
ranging from Alzheimer’s disease to multi-infarct dementia to mixed dementia.
In fact, her clinical picture was very irregular and did not follow a pattern of
progressive decline. Despite her very poor performance upon admission on one
cognitive test (the Blessed), she performed much better on the Mini Mental
State Exam (MMSE) three years later (scoring 21 out of 30). Reports of her his-
tory of continence also varied enormously, with clear improvement over the
most recent year.

Since her admission, Mrs. Fine had moved to four different units, including
two admissions to Morgan II. The moves were generally a result of her aggres-
siveness toward better-functioning residents on the other units. A fall just a
year after admission left her wheelchair bound, incontinent, and angry. Since
her last return to Morgan II, she had received physical therapy, was able to walk
again with a walker, and regained continence. Her heightened independence
had improved her mood considerably.

About a week prior to my coming to the unit, Mrs. Fine had just returned
from a brief hospital stay following left-side weakness and an inability to speak.
Tests indicated that she had not suffered another stroke, but more likely, a tran-
sient ischemic attack. Additional neurological assessments showed that she had
mild cortical atrophy, no new infarcts beyond the earlier one on her occipital
lobe (side not indicated). There was also a mild flattening of tissue (the nasola-
bial fold) on her right hemisphere. The neurological exam showed signs of
dementing disease, most likely Alzheimer’s, that was believed to have affected
her both short- and long-term memory. Since returning from the hospital, her
aphasia also seemed somewhat more marked.

**This Unplanned Substudy**

I had been on the unit for about three weeks when Mrs. Fine approached the
nurse’s station, where I was sitting. She was very upset, so the nurse gently asked
her to calm down and went to her room to see what was upsetting her. A few
minutes later the nurse exited her room, after assuring Mrs. Fine that her pho-
tographs were still there—a periodic worry of hers.

Mrs. Fine then turned to me and beckoned me to join her in her room. This
caught me completely off guard. I had not really conversed with Mrs. Fine be-
fore, except casually while moving about during the course of my observations
on the unit. Perhaps she had sensed my interest in her; if so, this showed an
awareness I had not come to expect from someone suffering from dementia.
Since I had never made demands on her, she may also have perceived me simply as nonthreatening company.

As I entered her room (the only single room on the unit), I commented on the many pictures she had displayed on her bulletin board and on how lovely her room appeared. “I did it myself,” she proudly proclaimed. This was the beginning of a two-hour-long visit. Mrs. Fine started showing me her pictures, but as she tried to describe each one, her aphasia interfered with her ability to express herself. In frustration at her inability to finish a sentence or locate the right word, she would pull back her head and groan dramatically. I resisted choosing words for her, so as not to rush her or impede her thought processes. However, if she were struggling exceptionally, I might ask, “Do you mean X?” She could then simply answer yes the majority of the time, or no, and try once again. In this way we slowly proceeded through the dialogue. After Mrs. Fine proudly pointed out pictures of her daughters and grandchildren, her eye caught one lovely young woman, and she began to sob. “That’s my Gilda, and how I loved her! And she died!” Gradually it came out that Gilda was her daughter, who at eighteen had died as a result of physician negligence. While the details escaped me, Mrs. Fine’s expression of suffering the loss of a child was clearly communicated, and her words and emotions moved me to tears.4

My own tears apparently touched her and she calmed down, smiled slightly, and continued showing me her pictures. When she came to a picture of her husband, she started to moan and shake her head. At first, I suspected that this was because he was deceased, but her tone of voice and gestures suggested that there was something more to her reaction. After we sat down, I admired the large framed picture on her nightstand of Mrs. Fine in a formal pose and fancy dress. The photograph prompted her to share the following story.

Mrs. Fine’s Story
Many years ago, at a party she attended with her daughter, a man approached her daughter, asking if he could snap a photograph of Mrs. Fine. Although reluctant at first, after some pressure from the man, Mrs. Fine finally agreed. Later she agreed also to have a picture taken with the man’s brother.

At that point in her story, Mrs. Fine opened the drawer of her nightstand and pulled out a picture showing her wearing the same dress, this time with the man in her story. Someone had jotted his name on the back of the picture, possibly as a reminder, suggesting perhaps that he was not familiar to her. They were standing side by side formally and holding hands. Mrs. Fine looked at me and said, “I never saw that man again.”

After the party, Mrs. Fine took the photographs to be developed at her local pharmacy. Her husband, who had returned early from a business trip, before going home stopped at the pharmacy to pick up some medicine for her. The
pharmacist looked at him in a puzzled way, wanting to know if he was her hus-
band, because he had seen her (referring to the photograph) with another man.

After hearing this, Mr. Fine grew suspicious, and upon returning home and
seeing the picture, he became incensed, convinced that his wife had become
involved with that man. He then went to visit Mrs. Fine’s sister and her hus-
band, Mr. Fine’s business partner, to see if they knew anything. Her brother-in-
law confirmed that she was seeing another man.

“What a lie!” Mrs. Fine complained to me, again getting upset, holding her
hands to her temples and shaking her head.

To punish her, her husband withdrew all their money from the bank and
gave it to her sister and brother-in-law. He then signed over his business as well.
She was left penniless and with a furious spouse.

I asked Mrs. Fine if she and her husband had separated because of this
event. She said they had not, but that he refused to talk to her, believing the
others over her. Even her daughter could not convince him of her innocence.

I asked if her husband had left any estate for her children. She said he had
not, but that they were nevertheless financially secure. However, she reiterated,
“But I have nothing, just this” (referring to her room), while her sister bought a
very big house with the money. She added that this same sister took all her
jewelry after she entered the nursing home, claiming that Mrs. Fine would no
longer need it.

Within two months Mrs. Fine’s husband was dead. She believed, in retro-
spect, that he knew the end was coming, which is why he hurried to transfer
their money and business to her sister, as punishment. “But,” she insisted dra-
matically, turning to me, “it was not the money that upset me; it was his going to
his grave, still not believing me, when never once was I unfaithful to him!”

Once again, she became upset, shaking her head and then tossing it back in
despair, while sighing in agony. I expressed my empathy and stated how very
difficult this must have been for her. “Exactly!” she agreed.

A couple of months after Mrs. Fine’s husband died, her daughter went to
another party, where she expected to see the man in the picture. He never ap-
peared. A few days later, the man who took her picture showed up at Mrs. Fine’s
door to inform her that his brother had died. He then explained how his
brother, who had been terminally ill, had been admiring Mrs. Fine, which is why
he had wanted to take his picture with her.

It was these events that had left her alone and penniless.

Mrs. Fine appeared relaxed after completing her tragic tale. Then she
smiled and wished me greater happiness in my life than the horrors she had
been meted. She asked that I not share this story with anyone on the staff for
fear it might get back to her sister and cause a family upheaval; however, she did
grant me permission to talk with her daughters.
Methodological Issues

Although I typically audiorecord and transcribe interviews that I conduct with family members, I did not expect to be gathering any formal life histories with residents of Morgan II, given the severity of their impairment. So I was unprepared to tape-record Mrs. Fine's story. Even if I had had my tape recorder with me, I suspect, Mrs. Fine would have been reluctant to let me turn it on, given her intermittent paranoia. Also, I would not have wanted to risk having a device interfere with her narration. In addition, as those of a cultural anthropologist, my transcriptions would have been used for analyzing the general content of the story, rather than for linguistic microanalysis, so I did not fear that the analysis would suffer by relying on my reconstruction of her story.

Soon after I left Mrs. Fine's room, I attempted to reconstruct and record our conversation and the detailed elements of her story as fully and accurately as possible, preserving quotes and her emotional expression as I remembered them.

Checking the “Facts”

On three subsequent occasions, Mrs. Fine repeated parts of this story, changing some of the details each time. The plot remained the same—her having been photographed with this man and her husband’s disbelieving her story. What differed were the identities of the relatives who had lied to her husband and who had personally benefited at her expense. On these occasions, Mrs. Fine substituted her daughter Ethel and her son-in-law for her sister and brother-in-law. Thus, there was some arbitrariness in the elements she had selected for her story. Because of these discrepancies and my curiosity about the veracity of her story, I decided to investigate some of its “facts.”

I discovered that the staff were inclined to discount her statements as fantasy even when they were not. One nurse said that Mrs. Fine had never lost a daughter and warned me not to believe her stories. However, the head nurse, who also distrusted many of her stories, and Kathy, another of Mrs. Fine's daughters, confirmed that a third daughter had indeed died as a young adult.

In talking with Kathy, I learned that Mrs. Fine had started telling some version of this story several months earlier. I also confirmed that Mrs. Fine's husband had died twenty years before her admission to the nursing home. About ten years after his death, Mrs. Fine met Mr. Haller, the man in the picture, at a party, and they developed a serious relationship that lasted until his own death eight years later, about two years before she entered the nursing home. The two men had not overlapped in time. Kathy felt that Mr. Haller had offered her mother companionship and had “doted on her.”

Kathy indicated that her father had never rejected her mother; he had
adored her throughout their life together, giving her whatever she wanted. Like Mr. Haller, he was a generous, loving man: “My mother had the distinction of being loved by two men in her life.”

She related that her mother was always saving money and was quite prudish. Kathy’s husband, during a later, impromptu telephone interview, stated up front that he did not like his mother-in-law and commented that she used to “boss around” her “spineless” husband, showing “little respect for him.” He added that Mrs. Fine was obsessed with money and was suspicious that others—even family members—were stealing from her. He also proffered the statement that Mrs. Fine’s sister, who supposedly had benefited from Mrs. Fine’s losses, was living “on welfare.” Both Kathy and her husband had independently alluded to Kathy’s sister’s having taken some of Mrs. Fine’s wealth—an apparently bitter issue within the family—but neither would elaborate.

Coherence and Dementia

I was struck by the apparent strength of coherence in this story as well as the unmistakable tragic content of its plot, in spite of distortions in the timing and identity of the characters. After describing some of the distortions, I will review the literature about coherence in dementia and then examine the coherence in this story.

Distortion in Mrs. Fine’s Story

There were several concrete elements in Mrs. Fine’s story that were inconsistent with the facts reported by her daughter. These included Mrs. Fine’s identification of the man in the picture as a stranger, the compression of time between her husband’s death and that of the man in the picture, and her allegation that her husband had left her penniless. It would be much too easy to consider the distortion as entirely the product of her dementia, which no doubt did contribute to it. However, to disregard Mrs. Fine’s story because of her diagnosis would be to ignore both the importance of her effort in constructing it and its potential meaning for her.

Embracing as authoritative fact the comments of Mrs. Fine’s family is equally problematic. Her daughter reported, for example, that Mrs. Fine’s husband had adored her. Suggesting otherwise, however, Mrs. Fine’s son-in-law claimed that Mrs. Fine had shown no respect for her husband. And Mrs. Fine reported that her husband died believing that she had been unfaithful. Perhaps the “truth” lies within each of these statements and somewhere in between. Each family member spoke from a particular perspective, a unique history of relationship with Mrs. Fine and her husband, and a selective memory of experience.

Still, the concrete information her daughter provided, to the extent it was
accurate, was useful for revealing how Mrs. Fine had significantly reordered sequential events in her life story as well as altered the identity of a principal character and the history of her relationship with him. The family’s factual data (dates, temporal sequence of events, and the identity of characters) can serve as a source against which to compare elements selected by Mrs. Fine in constructing her narrative. Although other comments from her family could also be used to interpret aspects of her story, they should not be regarded as the “valid” external indicator of historical “truth.” Rather, they should be considered as additional narrative fragments, at various times confronting, informing, reinforcing, or conjoining with fragments of her own memory.

Coherence and the Language of Dementia

The literature on language production in dementia suggests that considerable loss of coherence occurs, particularly in the ability to create logical time sequence (temporal coherence) (Ellis 1996, 483–486) and sticking to the point (thematic coherence) (Davis et al. 1997; Ellis 1996, 488–490; Thompson 1987, 148–149; Cherney and Cantor 1992, 124). Much of this literature asserts that with dementia, and in Alzheimer’s disease (AD) in particular (Hamilton 1994, 27), speech is typically fluent, but irrelevant, circuitous, and empty of meaning (Thompson 1987, 147). People with this diagnosis typically are reported to have trouble selecting appropriate details, distinguishing fact from fiction, and determining logical sequential order. Still, their language manifests grammatically correct sentence structure and does not appear unusual except when considered in the context of the larger discourse (Ellis 1996, 474; Crisp 1959, 134). Thus communication, and coherence in particular, appear to be a particular problem for elders with AD (Ellis 1996, 477).

The literature on coherence in AD suggests that in more advanced AD, speech difficulties extend to grammatical errors and are characterized by increasing difficulty in ordering events (problems with temporal coherence), by difficulties in determining logical sequential order (Ska and Guenard 1993, 10–11), and by the inadequate usage of referents (that is, corruption of thematic coherence) (Ellis 1996, 483–490).

More recently, however, researchers have been arguing that the discouraging assessment of speech in those affected by dementia may be indicative of the conditions under which that speech was produced (Davis, O’Neil-Pirozzi, and Coon 1997; Crisp 1995, 134) or of cultural characteristics not taken into account by objective assessments (Bower 1997, 1999). Dismal assessment of the language productions of demented elders may also result from the artificial experimental conditions under which language was produced (Hamilton 1994, 19; Bower 1999, 10; Crisp 1995, 134) as well as from the power differential this creates between subject and researcher (Sabat 1999, 116). Like other researchers of narrative practice (e.g., Gubrium and Holstein 1998), sociolinguists Hamilton (1994, 27)
and Sabat (1999, 117) argue for the importance of contextual and dialogic factors in interpreting their narrative production.

Hamilton (1994, 30) addressed the value of maintaining a personal, sensitive, engaged approach to working with demented elders, and Sabat (1999) underlined the importance of giving them adequate time to find words and to organize thoughts. His unobtrusive “indirect repair” allowed him to periodically confirm his understanding with a simple “do you mean X?” while allowing the elder to take charge of her dialogue. Institutionalized elders in Scotland shared surprisingly coherent poetry with John Killick (1999), after he worked to gain their trust and let them direct the communication. Killick highlighted the importance of empathy, silence, and even self-effacement in promoting dialogue, thus enabling elders to produce language that was more coherent than that suggested by the literature.

**Textual Coherence in Mrs. Fine’s Story**

Unlike her diagnoses, which seemed to vary as much as her symptoms, Mrs. Fine’s narrative seemed to have coherence far in excess of what one might expect from someone with dementia, particularly of the AD type. Perhaps her apparent coherence was enabled by the minimalist position I assumed as the lesser actor in our dialogue, quietly helping her complete her words, without imposing my own thoughts. In fact, she led the entire narrative event, from her invitation to me through to the completion of her story.

Despite the apparent coherence of her story, I decided to examine its formal coherence by turning to coherence criteria defined by linguist Charlotte Linde (1993). Like Hamilton and Sabat, Linde locates coherence not in “a disembodied text,” but in the “cooperative achievement” of the discourse participants (Linde 1993, 18). Linde argues that the life story coheres if it (1) has a reasonable narrative structure, (2) follows coherence principles, and (3) provides a socially shared coherence system.

**A Reasonable Narrative Structure . . .**

Life stories have reasonable narrative structures if they begin with an orientation (for example, the party Mrs. Fine described), continue with a sequence of events (such as the events following the party), offer an evaluation (her husband’s misjudgment and the injustice she suffered), and end with a coda (her bidding me a better fate). Several writers have referred to this principle as manifesting “emplotment” (Mattingly 1998; Bruner 1991). Mrs. Fine’s story clearly satisfied this criterion.

**. . . Follows Coherence Principles**

To satisfy coherence principles, a life story must also present a rich account, articulate a clear sequence of events, and show plausible causality. It was here where
Mrs. Fine’s story was a bit shakier. Certainly she presented a rich, even moving account, which was especially impressive given the severity of her speech difficulties. Moreover, although some of the events were out of order, her reconstructed sequence was logical. Whether the series of events she presented could have led to her husband’s actions would have depended both on her husband and on the history of her relationship with him. The evaluations by her daughter and son-in-law of the relationship between Mrs. Fine and her husband clashed somewhat and only served to confuse matters. It is certainly possible that a jealous, angry husband could be provoked to act in this way and that his actions could have led to her poverty. Because he died soon afterward, there was little time for him to reassess and possibly reverse his actions. Her “consequential” living in a small room of a nursing home was evidence to her of her great material losses. Yet anyone who knew the great cost of nursing homes, and especially of private rooms, would realize that she did not ultimately arrive here out of poverty.

...And Provides a Socially Shared Coherence System
Mrs. Fine’s story is readily recognizable as a tragedy (Bruner 1991, 11–12). As the listener, I appreciated the implications of her unfortunate losses (her husband, her property, his trust) and the social injustices she suffered (his misguided disbelief in her; the gains of her dishonest brother-in-law; her institutionalized existence). What began as an innocent, kind gesture (agreeing to have her picture taken) turned into the source of an indisputably tragic outcome. Not only does her story capture tragic human plights; it is also “worth telling”—two strong features of socially coherent narrative (Bruner 1991). She offered a classic canonical script—an unjustly assumed breach of marital fidelity, resulting in a violation of another canon: marital trust.

By Linde’s (1993) criteria, Mrs. Fine’s story had considerable coherence in spite of the questions it raised about her husband’s responses. Her narrative structure, the sequence of events, and the tragic plot all contributed to a coherent story line that carried a persistent emotional truth.

It was not coherence, but the plausibility of some of the events, that seemed questionable. I did not understand, for instance, why Mrs. Fine, rather than the man who shot the photograph, was responsible for having them developed. The photographs that I saw were in fact large in size and apparently professionally processed, not developed at a local pharmacy. In addition, it seemed odd that the pharmacist to whom she took the pictures to be developed would have looked at them and, even more odd, taken the liberty to ask Mr. Fine if he was her husband, although it is hard to know how her local pharmacy actually conducted business, from the perspective of Mrs. Fine, as a shopper there, accumulating experiences that formed the basis of the memories, from which she drew fragments. It seemed surprising too that the man who took her picture
came to her house to tell her of his brother’s death, even though she claimed not to have known him. Still, there may have been little details—background knowledge (Bruner 1991, 10)—that she had not shared with me that might have provided a context to clarify her construction (cf. Gullette 1997, 204). Although a greater understanding of these details might have improved the plausibility of these events, it would not have affected the degree of coherence in Mrs. Fine’s story.

Beyond Textual Coherence: “Truth,” the Self, and Meaning

Even though Mrs. Fine’s story was coherent, it departed from historical reality (Kohli 1981, 64). Aside from some ambiguous or questionable details in her content, her reordering of events and misrepresenting as a stranger the man with whom she had experienced an eight-year relationship call into question the external validity of her story. In this section, therefore, I will consider the relevance of facticity—or externally verifiable “historical truth” (71)—to coherence in life stories. However, I will look beyond Linde’s textual coherence principles to other ways in which an elder’s life narrative may achieve coherence. Last, I will examine the relationship of life stories to issues about the self and meaning for elders.

Coherence and the Question of Facticity/“Truth”

Subjective “Truth” versus Performative Coherence

In contrast to most analysts of life stories, Peter Coleman argues that a life story must have “truth value” (1999, 134)—but of a subjective “truth” as understood by the narrator, not of one determined by an objective observer (137). In contrast, Denzin locates the importance of coherence in autobiographical narration entirely beyond the truth value of the narrative: “The point is not whether biographical coherence is an illusion or reality. Rather, what must be established is how individuals give coherence to their lives when they write or talk self autobiographies” (1989, 62, cited in Gubrium and Holstein 1998, 165; emphasis added). In other words, coherence is produced in the process of creating or performing the life story (cf. Mattingly 1998, 43).

Narrative Truth: From Coherence within the Text to Coherence within the Person

Similarly, Bruner argues that life narratives can only reach “verisimilitude,” not empirical verification (1991, 4). Linde agrees but focuses mainly on coherence within the boundaries of the text (1993, 220; cf. Mattingly 1998, 34). She later adds that the value of a narrative is in its ability to help organize a speaker’s understandings of her “past life, current situation and imagined future” (1993,
This demands a coherent, constantly revised life story that expresses “who we are and how we got that way” (3). Coherence systems provide language for creating that new self, even if that self or the story is a fictitious one (189; Polkinghorne 1996, 90–1). Linde has shifted from coherence within the text to coherence within the person.

For Bruner too, the point is not the constitution of the text, but on “how it operates as an instrument of mind” in constructing reality (1991, 5–6). “Rather than referring to ‘reality,’ or ‘historical truth,’ the life story actually constructs its own ‘narrative truth’” (13; Polkinghorne 1996, 89; cf. Mattingly 1998, 40–2) that has particular meaning for the narrator (Polkinghorne 1996, 78). Crisp too, describes narratives as the “externalized demonstration of internal mental processes,” (1995, 138) without reference to their historical accuracy. For others, it is within this narrative that identities are constructed (cf. Jamieson and Victor 1997, 170; cf. Coupland and Coupland 1995, 94).

“Coherence Work” as Self-Constituting and Integrating: The Forming of Emotional Truth in the Self

For Moody, also, the “coherence work” of late-life reminiscence may involve creating a fictional or metaphoric version of the self (1993, xxxiv). Ewing (1990) explains how people create new selves (or self-representations) as they proceed through life and engage in new experiences with different people. The need for coherence becomes apparent only when we encounter a disruption or new life experience that cannot fit into our existing life narrative (Linde 1993, 17); the life story must then change to accommodate that event. The readjusted life story helps to preserve or reproduce the sense of continuity of one’s self (Kaufman 1988, 219).

Fragmentation occurs when a person’s available self-representations (or selves) in a new setting or in new interactions with others no longer correspond to the person’s prior experiences (cf. Randall 1996, 237–238). Whenever this leads to the loss of a sense of wholeness or integration, or when the person is challenged by a new situation, the person creates a more adequate self through a new synthesis and integration in her life story (Ewing 1990, 262).

In narrative productions, self-constitution occurs because of the ability of the narrator to separate herself from the self she is creating (Ewing 1990, 262; Linde 1993, 105, 122). Although distinct selves are created in response to the demands of new life contexts, an illusory experience of wholeness, coherence, or “unity of feeling” is achieved because each self-representation organizes fragments of experiences as if they were constant and timeless (Ewing 1990, 262; Mattingly 1998, 107). Coherence is a symbolic process that depends more on that unity of feeling—an affective state—than on logical rules of text or even on actual past experience (Fernandez 1986, 161; cited in Ewing 1990, 268). It forms its own constant emotional truth.
For Mrs. Fine, suffering both from dementia and the dissatisfaction of her life circumstances, two sources of fragmentation tore at her sense of wholeness. First, her dementia challenged her sense of cognitive integration. Second, her sense of self-integration was challenged by her depersonalizing living conditions in an institutional setting that neither valued nor reinforced her personal history and biography. Finding her current residence in the nursing home beyond her control and comprehension, she attempted a “symbolic reworking” (Lovell 1997, 361), “restorying” (Randall 1996), or “mythological rearranging” (Hankins 1981, 203) of her everyday experience.

Rather than unraveling, Mrs. Fine constructed a narrative that provided an anchor from which she could affirm her identity in the midst of potential chaos and threats to it (cf. Kohli 1981, 71). She wove her story out of “meaning traces” (Polkinghorne 1996, 88) or fragments drawn from her dwindling memory of real and imagined experiences and other texts available to her (cf. Crisp 1995, 137). The powerful self-reinforcement and integrative functions of the narrative were far more significant to Mrs. Fine than was the departure of its content from historical reality.

The Meaning of Life Stories

Most life narratives are concerned with negative events, suggesting that trouble—frustration, confusion, and misunderstanding—drives people to communicate their life stories (Ochs and Capps 2001, 145–146; cf. Tarman 1988, 185–186). A life story helps make sense of troubling life experience (cf. Mattingly 1998, 25) by reconciling outcomes with expectations (Ochs and Capps 2001, 134). It also creates a sense of order out of potential meaninglessness (Tarman 1988, 185–186). For Mrs. Fine, living in a small room on the locked dementia unit was difficult to comprehend. Her life story helped her reconcile her existential condition with her expectations for something greater by explaining how she ended up there. Although it did not enable her to resolve her situation, it did help her to achieve psychological closure (Ochs and Capps 2001; Polkinghorne 1996, 89).

Meaning in Mrs. Fine’s Story

According to Ricoeur (1984, cited in Mattingly 1998, 38), the meaning of a story is organized around its ending. The narrator’s “existentially meaningful” plot (Lovell 1997, 355) allows events to unfold toward that ending by organizing reconstituted events and memory fragments—actual, fictional, and borrowed—in a way that enables the narrator to make sense out of her current situation.

Mrs. Fine’s narrative ended with her unhappy living situation. In creating a meaningful story, Mrs. Fine reworked some of the characters and their relation
to her. She transformed Mr. Haller from a companion of many years into a stranger. She re-created her husband from an allegedly “adoring” (Kathy’s view), perhaps “spineless,” spouse whom she dominated (her son’s-in-law view) to a rigid, rejecting, dominating figure, unwilling to listen to his own family. Was she trying to create a husband whose qualities she might have preferred? Perhaps. Was she working out guilt for having supposedly “bossed around her husband”? Possibly. More likely, she reworked her memory fragments, however distorted, about her husband’s behaviors in a way that made sense of the story’s ending: the plot required that he reject her, to help explain her current plight. How else might she have come to live in her tiny nursing home room?

By providing a plot directly related to her current situation (her story’s ending), Mrs. Fine’s narrative protected “against the chilling possibility” that her life and current status were “random, accidental, unmotivated” (Linde, 1993, 6; Tarman, 1988), in short, meaningless. Her plot helped her make sense out of events, regardless of whether they were true (Mattingly, 1998, 37). Her photographs provided the trigger for creating meaningfully plotted events—a strategy of survival (Crisp, 1995, 138; Mattingly, 1998, 107)—which is why mislocating them was so upsetting to her. Her compelling “need” to tell her story (cf. Mattingly, 1998, 45) was also understandable: it reaffirmed both order in the universe and her place within it.

Mrs. Fine’s narrative also imparted a moral perspective to her life (Mattingly, 1998, 29). It served to destigmatize her plight and to exculpate her (cf. Lovell, 1997) from blame and responsibility for having arrived there. Through narrative, she was able to transfer the moral responsibility for her current situation from herself to others—the solicitous photographer, her dishonest brother-in-law, her disbelieving husband. Perhaps this is why she seemed so calm, controlled, and even relieved after she finished telling me her story (cf. Crisp, 1995, 38).

Mrs. Fine’s narrative was a canonical tale (cf. Bruner, 1991, 12) with a twist. That fateful party, the inquisitive pharmacist, the lying brother-in-law all contributed to her current plight. Hers was not the typical story of a cuckolded husband, but of a wrongly accused wife: not of truth prevailing in the end, but of dishonesty gaining victory (her brother-in-law benefiting from her losses). It is a story of undeserved injustice (her living in a single nursing home room with very little) and undeserved gain (her sister ending up with a huge house). There is no resolution here, only an explanation for enduring angst—a sustained emotional truth. She is both victim and heroine, admired by a stranger but rejected by her husband, accused yet innocent; in short, she is the central character of a powerful, yet tragic, plot.

Such a central role can be powerfully sustaining, providing the “lifebuoy of
an identity that is drowning” (Gerbeaud 1987, 138, cited in Crisp 1995, 138). The dialogic process in which she took charge of her production, while gaining affirmation from me, the listener, further reinforced her sense of self-worth.

Mrs. Fine’s tale is also metaphorical. The invalidation, injustice, and particular losses she suffered in her story can be matched in real life by the invalidation she experiences in response to her dementia; the injustice of living in an undesirable situation; and the loss of her freedom, autonomy, and frequent contact with loved ones.

Discussion and Conclusion

Narrative analyses tend to emphasize the interpretive value or narrative meaning of a story for its narrator rather than the correspondence of the narrated events to an objective reality (Polkinghorne 1996; Mattingly 1998, 39–42; Randall 1996). When a person tells her life story, no matter how fictitious the account, her narrative does not reflect the past, but rather “becomes the past” (Randall 1996, 230; emphasis added). Thus an authentic life story is not one that corresponds to an objective indicator of the “truth,” but rather one that is “made” the narrator’s own” (Kenyon 1996, 28–9).

It is not accidental, then, that narrative analyses of persons undergoing aging, illness, or major disruptions in their lives have drawn primarily from interpretive phenomenological approaches (Rabinow and Sullivan 1987), rather than structural or extreme postmodernist ones. The former approaches focus, not on coherence in the text, but on coherence for the subject. They examine the ways in which people construct their identities and inner worlds in order to make sense of their experiences and to preserve a sense of continuity (Mattingly 1998, 107) or restore a sense of order in their lives. These are the most pressing concerns for those threatened with its dissolution, however illusory these may be (Ewing 1990).

Phenomenology embraces the very concepts—subjectivity, inner experience, unity, “truth,” and continuity—that structuralism and postmodernism reject (cf. Mattingly 1998, 140–143). Postmodernism favors partializing concepts—discontinuity, fracture, and contingency—that emphasize the ephemeral quality and arbitrariness of the story. However, even though the content of a narrative may appear arbitrary, the material and existential conditions that gave rise to it are subjectively experienced as very real by the author. This is why Mattingly astutely distinguishes narrative analyses that concern written and oral texts from those that concern lived experience and inner meanings (44).

A danger in focusing strictly on story (or text) is that every story is not equally validated by other cultural scripts. For example, for those with dementia in a medicalized setting, the disease model of dementia serves to invalidate affected persons’ subjective feelings, thoughts, experiences, and emotions as dis-
torted (empirically “untrue”) artifacts of disease and sees their stories as irrational ramblings (Crisp 1995). Extreme postmodernism, despite its celebration of difference, unwittingly reinforces biomedicine’s invalidation of the demented elder by rejecting the validity of the “truth” of her subjective experience. Thus, biomedicine, with its insistence only on empirically validated truth, and postmodernism, with its rejection of all “truths,” both effectively invalidate the subjective experience of elders with dementia.

In discussing the many narratives produced by her cognitively impaired mother, Jane Crisp (1995) recognized a coherence and sense in them that were not apparent to an outsider. Given her perspective about her mother’s history of fears, preferences, and position in her marital relation, Crisp was able to see how her mother’s stories revealed these aspects of her past or served to reverse previous injustices. Crisp introduced external information, not to validate facts or events from her mother’s stories, but to elucidate their possible relevance in light of her present situation.

Because of the compromised rationality of persons with dementia, there is considerable skepticism about taking seriously what they say. However, even when what they say does depart from verifiable facts, elders who tell stories may present a coherent picture, as we saw with Mrs. Fine. It is not the actual historical facts, but their construction of a new story that provides meaning to the narrators and gives us clues to their lived experience.

We must ask whether anything can be gained by our turning to external sources of information to understand the stories of persons with dementia. I would argue that we are treading on potentially dangerous territory by risking the elevation of some voices—and narrative truths—over others on realist grounds. To the extent that additional information can reveal sense in a story that would otherwise be disregarded as irrelevant, it should be embraced. External information that offers factual information about dates, events, and characters and clues about their reworkings may also advance our understanding of the story’s meaning for the elder. However, when these sources are used to disconfirm (or even affirm) an elder’s story on the basis of its lack (or presence) of correspondence to external indicators of “truth,” it risks disempowering and invalidating that elder.

I frankly am unsure of how much I gained by talking with Mrs. Fine’s daughter and son-in-law. At the time of Mrs. Fine’s narration, I was too caught up in her story and her struggle in communicating it to worry about any correspondence of its elements to empirical facts. However, gaining confirmation about the death of her daughter did make the rest of what she said more convincing to me. But it did so not because it gave me license to believe the rest of her narrative. Rather, it made me aware of the lasting effect of significant events in her life, whether she suffered from dementia or not. Even though several elements of her subsequent story were not historically verifiable, that was beside the
point. Her narration made a convincing case of the significance of its narrative truth in the context of her unhappy living situation and the power of her own agency in reconstructing sense in her existentially and materially constrained life.

NOTES

1. See also the special collection in the Journal of Aging Studies 12, no. 2 (1998).
2. Exceptions to this include Sabat (1991, 1999) and Hamilton (1994, 1999). These researchers, however, examined narratives produced by elders, but not necessarily their life stories. More relevant here is the work of Crisp (1995), who examined the stories of her mother, who suffered from dementia.
3. Although the two tests measured somewhat different cognitive elements, the Blessed, for example, examining information, memory, and concentration; and the Mini Mental State Exam (MMSE), memory orientation, concentration, language, and constructional ability (Sano and Weber 2003, 27–28), the difference in Mrs. Fine’s performance went beyond differences in the tests. It reflected differences in disposition toward being tested as well as actual differences in her in cognitive status during times of testing.
4. This recalls the way in which Sharon Kaufman found the tragic stories of her informant’s lives “almost too much . . . to bear” (1988, 222).

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